

Recent Long-Term Morbidity Studies in Hagerstown, Md.

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Origin and Development

THE Hagerstown studies originated in 1921 with a survey of the frequency of sickness in 2,000 randomly selected families. The survey extended over a period of 3 years and covered 7,800 individuals representative of the age, sex, and socioeconomic composition of the community. Interviews were conducted at intervals of 6 weeks over periods ranging from 1 to 3 years. During the same period, school absences for illness, anthropometric measurements, physical defects, and dental examinations were recorded for 4,000-7,300 school children.

For 5 years following 1923, annual measurements of height and weight were made on Hagerstown school children, and the results were published in a series of growth studies. During the same period, morbidity records of children were maintained. Later, in 1928, an audiometric survey was conducted to determine the extent and nature of hearing defects in a cross section of the school population.

Five years later, Public Health Service investigators returned to Hagerstown and resumed the studies on growth of school children. The results were compared with earlier measurements to determine the effect of the economic depression on growth. Starting in 1935, immediately following the growth studies, records were kept on the morbidity of school children for a period of

2 years. These records were later used in a study comparing child morbidity at three different periods of time.

Up to this point these surveys and studies were independent and were largely planned without interrelationship in content or objectives. But all the original records are still available.

In 1937, the child hygiene office undertook a series of integrated studies of school children. The concept of follow-up or long-term studies developed shortly thereafter, and the local office of the U. S. Public Health Service was established on a permanent basis. The observations recorded since that time have been of three classes: (1) systematic studies of various aspects of child health, (2) by-product data of special health activities preserved on the assumption that they might have eventual usefulness, and (3) data collected for the purpose of comparison with earlier records, i.e., for long-term studies.

The list of items is imposing. In addition to further school morbidity records, dental examinations, and height-weight records, there are data from chest X-rays, heart examinations, illness and death from cancer, Selective Service examinations, pneumonia antigen immunizations, hearing and speech surveys, venereal disease records, mortality records of husbands and wives, marriage and divorce records, and the results of a 1943 re-cavass of the sur-

living families of the 1921-23 survey. A full list of the studies appears as the appendix. During the past decade the staff has been engaged part of the time in organizing the records into a family file in order to facilitate further analyses. This project is nearly completed.

It can be inferred that cooperation between local authorities and physicians and the U. S. Public Health Service staff has been excellent. All data requested by the staff have been made available. In exchange, the staff has rendered service in kind by assisting local health agencies in the development of forms and record systems and in tabulation and analysis of data for administrative purposes. Cooperation is maintained, in part, through a planning committee composed of three members of the medical society, the County Health Officer, and the head of the Hagerstown office of the Public Health Service. Proposed projects are discussed by this committee which tells Hagerstown physicians about the aims and information desired and asks them to cooperate in furnishing the necessary data, with the understanding that all material will be confidential. In the case of projects which involve a canvass of households, it is equally important that physicians know about the project and its aims. Thus it is possible to avoid embarrassment of the physician when patients tell him that they have been called on and question him about the purpose of the study. The smoothness of relationships over the years should not be interpreted as license to neglect the matters just described.

Methodological Problems

Long-term or longitudinal studies conducted or in process thus far include: a comparison of Selective Service examination defects with defects recorded among the same individuals when they were school children in 1922-28^{1, 2}; a study of chronic sickness in relation to survivorship 20 years later³; an esti-

mate of the incidence or rate of occurrence of new cases of chronic disease⁴; a report on chronic illness in families in relation to changing economic status⁵; the socioeconomic and illness histories of indigent medical patients; chronic illness in relation to morbidity 20 years later; and a study of incidence of cancer in several generations of families. These studies have been sufficient to reveal several problems of methodology, some of which appear as problems peculiar to longitudinal studies.

Validity of reporting is, of course, the fundamental problem in all illness studies. Hagerstown data have been collected in a variety of familiar ways: house-to-house canvass; physical examinations; school, hospital, clinic, and health department records; verification with physicians; and death certificates. For the most part efforts to obtain complete and accurate data have been no different from those of other careful studies. An advance may be found, however, in the current study of familial cancer which is using reports of household informants, physicians, hospital records, cancer registers, and death certificates, checking each source against the others.

Partly in an effort to obtain a complete record of chronic illness prevalence, the original 1921-23 interviewers made repeated visits over a period of more than 2 years, on the assumption that occurrence of acute phases would lead to fuller reporting. The 1943 re-survey, however, was a one-stop canvass. A surprising and thus far unexplained finding of the comparative data is that 60 percent of the surviving persons reported as having chronic conditions in 1921 were reported as having no illness in 1943. An additional 28 percent complained of some other disease in the second survey. Differentials by diagnosis are being studied. It will not be possible, however, to determine from

existing data whether the phenomenon arises from change in informants, from actual recovery, from "recovery" from a psychosomatic illness after the passing of an emotional situation, from having lived so long with illness that it becomes part of one's normal life, or from the presence in 1943 of a more serious or painful disease "preferred" by the respondent over the original condition. Whatever the explanation, the phenomenon itself indicates that intervals between surveys should be shorter and that procedures for obtaining specific diagnoses should be more objective.

We are inclined to the position recently stated by Collins and Woolsey⁶ that further advances in valid sickness reporting by diagnosis for a representative sample of the population will occur only after the introduction of new techniques, and that this position is particularly applicable with reference to longitudinal studies requiring frequent reporting. Two techniques which should be followed closely are: (1) the multiple screening examination,^{7,8} and (2) the symptom check list.⁹ Both are still in exploratory stages and merit considerable attention. Maintenance of health counseling centers for families¹⁰ or for middle-aged and older people could also be useful sources of data if they are established in this country.

The familiar problem of reporting validity with reference to the relationship of the informant to the person reported upon arises in a new light. Housewives reported on their children in 1921, but by 1943 many of the children were adults reporting for themselves or being reported upon by wives. Moreover, the grown-up children of 1943 were often called upon to report for their aged parents who were the informants of the earlier period. Current Hagerstown studies indicate that informant relationship is a significant factor and, hence, it must be presumed

to influence the findings of long-term studies. It is quite possible that the high proportion of persons presumably ill in 1923, but who were reported well in 1943, may be due to this factor. In the earlier survey these people were, for the large part, reported upon on the basis of their parents' observations, whereas in the second survey they reported their own physical status or that of their spouses.

A variation of this problem is that 1943 informants were asked to report on persons who had lived apart from the family for any number of years up to 20. The Hagerstown staff has compared chronic disease prevalence rates in 1943 among persons living in the same dwelling as in 1923, among persons living in the city but in a different dwelling, and among persons living outside the city. When age is held constant, chronic illness rates were, in this instance, nearly identical.

This finding would indicate that the volume of chronic illness due to all causes was approximately the same whether persons being reported upon resided in the same household or resided elsewhere in 1943. However, the same data indicate that the informant's knowledge of specific disease diagnoses is less complete for persons who had moved away. Illnesses of unknown cause constituted 5 percent of all illnesses among persons living in the same house as in 1921-23, 9 percent among persons in a different house in the city, and 35 percent among persons who had left the area and who, consequently, were largely reported upon by remaining relatives. This relationship holds irrespective of age.

A problem peculiar to the long-term study is that the original population cohort declines from year-to-year, by reason of emigration, death, or other separation. For some types of studies considerable reconstruction can be accomplished by using nonmigrant rela-

tives as informants; by following the individuals themselves, if they are not too far away; and by use of death certificates. Children who have left the family can be traced to their new homes. There will always be, nevertheless, a residual of families and persons who have disappeared altogether. The question then arises as to what biases may have been introduced into the cohort surviving at subsequent periods. Analysis is now being made of the 1921-23 illness prevalence and of other characteristics of families who had disappeared completely by the time of the re-survey for comparison with similar data for those who were located or traced in 1943.

The problem of the interval between observations in long-term studies, already mentioned in connection with validity, arises in at least one other situation. In a study on the incidence of chronic diseases, for example, it was necessary to estimate the rates of occurrence of new cases for shorter periods of time by interpolation between the periods of actual observation. Thus, in order to get true incidence rates, the period between observations should be short enough to obtain the time of onset of an illness or disability with a reasonable degree of reliability. Collins met this problem in the Eastern Health District study of 1938-43.¹¹

The Promise of Longitudinal Studies

The Hagerstown Studies have been pioneers in revealing the needs for, and difficulties encountered in, long-term studies. Many of the aforementioned problems can be avoided by setting up studies which are initially designed as long-term in nature and planned to provide such knowledge as can be obtained only through a longitudinal method of approach. We suggest three broad areas in which such studies have much to offer.

Incidence and progress of chronic illness.—With the increasing emphasis of

public health on chronic diseases, well-planned longitudinal studies are needed to provide information on the incidence and progress of these illnesses. At present, knowledge of the incidence of chronic illnesses is meager. The re-survey material in Hagerstown has provided general information on the age-specific rate of occurrence for all chronic complaints combined. Yet further information is needed on the incidence, by age, of specific illnesses and on the rate at which such illnesses become handicapping or disabling. It is also desirable to know the frequency of attacks of acute phases of chronic diseases. Such figures would provide an intelligent basis for planning medical care programs and health funds. They would give a foreknowledge of the needs for chronic disease hospitals, equipment, and personnel. They would provide basic data with which to plan gainful employment for the aged and retirement and activity programs.

Changing patterns of chronic illness may result not only from actual changes in the incidence of disease or from shifts in the age distribution of the population. They may also arise because of changes in diagnostic terminology or developments in the quality and extensiveness of diagnostic techniques. Since the events leading up to chronic illness, methods of detection, and the course of disease are dynamic in nature, frequent longitudinal observations are the only practical method of obtaining reliable information.

Illness and socioeconomic factors.—The two-way relationship of sickness and socioeconomic factors has been of concern for a long time, but there is less known about it than remains to be discovered. The principal reason is that sickness and the individuals and circumstances in which it occurs are complex and dynamic in nature. The order of events, if not actual processes, must be observed in time sequence, and this is

the essence of long-term or longitudinal studies.

One of the challenging problems is that of unraveling the long-known association between illness and related factors. The association is not altogether clear-cut as to total illness save for the lowest income families. Downes finds considerable evidence, however, that some conditions such as rheumatic fever, pneumonia, and tuberculosis find a favorable environment among low-income populations.¹² Perrott and Sydenstricker found that families which had suffered severe income losses during the early 30's tended to have more illness than other families.¹³ It was not until the 1921-43 Hagerstown data were analyzed, however, that low-income status was shown to be a definite consequence of chronic illness. Present conclusions are based on a small number of cases and the data are subject to the limitations mentioned earlier. The findings should be verified through further studies and the actual process examined in terms of extent of disability, wage losses, treatment costs, and other explanatory factors.

Lowered economic status is only one of the probable effects of illness on individuals and families. General observation, at first, and, more recently, actual studies have shown that families with health problems are more likely than others to have problems of maladjustment, disorganization, and delinquency.¹⁴ Families may have to modify aspirations for their children and suffer loss of status in the community. An afflicted breadwinner may lose self-respect and his normal familial role. The list of possible effects could be extended; enough have been mentioned, however, to indicate that there is a significant role for the longitudinal study.

The reverse of the situation just mentioned is the influence of social and economic circumstances in producing

illness. It has long been supposed that certain concomitants of low income, such as inadequate housing, lack of education, insufficiency of medical advice, and undernourishment, may give rise to certain types of illness. In some instances, such as pellagra, the evidence is quite clear¹⁵; in others, such as housing, the actual chain of conditions has not been demonstrated¹⁶; and in still others no association has been shown. The current Hagerstown study of cancer is expected to indicate whether there is a tendency toward familial concentration of this disease as has been shown for chronic conditions in general.¹⁷ Observations are being extended over three generations. Whether or not techniques now available are adequate to identify psychosomatic conditions and possible family concentration is open to question, but it would seem worthwhile to test them.

The practical values of longitudinal studies of the types suggested above are obvious to all who are concerned with the various manifestations of social pathology and with the possibility of decreasing the proportion of diathetic, indigent, maladjusted families.

Illness and treatment programs.—Longitudinal studies can be employed to throw further light on numerous questions regarding the use and effectiveness of treatment programs. One group of questions would include such items as: How do people discover the need for diagnosis? How long do they wait to get it? If it is postponed, why? Where do they go and how do they decide where to go? To what extent do people make use of detection centers and other facilities for regular and free diagnostic services? Similar items revolve about the question of obtaining treatment once a diagnosis has been made.

Another set of problems has to do with the effectiveness of diagnosis and treatment. Can the frequency of attacks be retarded? Can symptoms or conditions

be cleared up? What differences can be observed in the course of sickness and in mortality rates of those who do and those who do not obtain diagnostic and treatment services?

The relationship of costs of treatment to its receipt, to how or where it is obtained, and to source of funds to pay for it represents a further area of investigation. What does treatment for specific conditions cost and how do people meet the costs? Since these conditions may be spread over a number of years, the longitudinal study may be the best device for collecting information.

Another area in which very little is known is that of medical and related treatment for the family of the individual with a disabling chronic condition. In prescribing treatment for an extended, expensive, disabling condition of the breadwinner, the housewife, or any member of the family, what attention is given to the effect on the total family unit? Is home care or hospitalization recommended with reference to its effect on the family? How frequently are other services, such as financial assistance or counseling, needed? Do families get them? How do they get them? How do they come to the attention of nonmedical agencies? In this case, as in others, family interviews would have to be supplemented with records of agency services.

Conclusion

Many of the problems identified above have been investigated by means of the conventional cross-section study; indeed it is through such studies that the problems have been defined. It is our belief that further progress depends upon use of methods involving frequent interviews conducted through extended periods of time and more objectively reported diagnoses.

Either of two basic sampling methods may be used. A representative initial cohort may be followed over such period of time as may be required. Observa-

tions can be limited to the original members of the cohort or extended to those added by marriage and birth. Migration out of the community would not affect the representativeness of the cohort, though in-migration would. For several of the studies mentioned, continuing representativeness would not be essential.

When a sample continuously representative of the community is necessary, it can be selected and re-selected on a geographic basis. A sample of this sort would not retain the same families or individuals except by chance.

One problem of a longitudinal study, particularly of the cohort type, is that repeated interviewing and questioning regarding health practices will of themselves improve practices. This limitation might well affect some types of studies but not all.

Frequent interviewing undoubtedly enhances the reliability of reporting sickness data but not the validity. Informant reporting, as in past studies, will be satisfactory for some purposes, but most studies involving prevalence or incidence of specific diagnosis will approach accuracy only as more objective reporting is developed. New techniques of mass diagnoses and symptom reporting should be explored thoroughly.

As a final word it should be observed that longitudinal studies will not increase in cost in direct proportion to the frequency of interviewing or the length of the time period covered. Long periods of repeated observation of a small sample will produce as many observations as one-stop interviews of a much larger sample.

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APPENDIX

Data on file in Hagerstown office of the Public Health Service:

1921-1928

- 1921-1924 Health Survey* (7,800 persons, 2,000 families). Original data sheets and punch cards which include illnesses, economic status, condition of housing, sanitation, etc.
- Childhood Morbidity* (7,313 children). Records of absenteeism from school.
- Physical Examinations* (5,233 children). Anthropometric data and obvious physical defects, including corrective measures where applied.
- Dental Examinations* (4,057 children). Dental charts and defects of school children.
- 1933-1937
- Height-Weight* (9,266 children). Longitudinal height-weight records for school population.
- Childhood Morbidity* (4,342 children).

Records of cause and duration of absence from school.

Anthropometric Data (3,551 children). Physical measurements and body build indices. 1937-1942

Height-Weight (12,400 children). Longitudinal records on school children with growth increments.

Childhood Morbidity (17,342 children). Record of cause and duration of absence from school.

Dental Examinations (14,163 children). Dental charts and other data showing defects.

Chest X-ray (9,768 children and adults). Records give date, number, and interpretations. Corresponding 14x17 plates on file.

Tuberculin Test (3,781 children). Results of both P.P.D. and O.T. tests with X-ray interpretation on same record.

Heart (2,407 children). Electrocardiographic and stethographic measurements. Tracings on file.

Physical Examinations (1,456 adults). Regulation selective service examinations by local physicians.

Mortality of Husbands and Wives (2,758 couples). Dates, ages, and causes of death of each couple. An additional 9,000 unpaired mortality records are also on file.

Marriage Records (15,078 couples). Names, ages, occupations, date and place of marriage, 1898-1938.

Divorce Records (2,600 couples). Names, ages, and occupations. Date and place of marriage and divorce.

1942-1949

Pneumonia Antigen (27,000 persons). Identifying data and dates of inoculation from 1940 through 1945, with concurrent data on pneumonia cases.

Family Composition (18,000 + families). Each card lists a family, giving names, birth dates, relationships and an index to Public Health Service records for each individual.

1943 Health Resurvey (1,600 families). Records of a resurvey of persons in the 1921-1924 survey. Includes location, state of health or illness, cause of death, economic data. Also recorded on punch cards together with certain of the 1921-24 information.

Cancer Records (450 families). Records of cancer cases and deaths in three generations of selected families.

Chest X-ray (18,900 persons). Film, data cards, and tentative diagnosis from mass X-ray surveys of 1948 and 1949. Retakes and final diagnosis on 14x17 plates.